

LTC ALERT!

California Partnership for Long-Term Care

What you should know about Long-Term Care

August 2001

The following article is a valuable resource that can be shared with your clients. Nationally-known journalist and Pulitzer Prize nominee, Beth Witrogen McLeod has written a series of caregiving articles to help readers address the sensitive issues and options of long-term care, including - Family Caregiving, How to Talk to Parents: "The Conversation," Community Resources and Self-Care, and the Rewards of Caregiving. McLeod is a journalist, speaker, and consultant on caregiving, spirituality, and wellness at midlife. Her most recent book is "Caregiving: The Spiritual Journey of Love, Loss, and Renewal" (Wiley, 2000).

How to Talk to Parents: "The Conversation"

It may be the most frustrating concern among Baby Boomers today: how to get parents to talk about long-term care needs—before a crisis hits.

A recent American Association of Retired Persons (AARP) survey found that two-thirds of adult children have never had this conversation because they don't know what information their parents need or where to find it. Talking to parents about private, uncomfortable matters is never easy. From long-term care insurance to end-of-life wishes, this conversation is loaded not only with concerns about maintaining independence, but also with unexamined family dynamics, sibling rivalries, and communication problems.

How do you know when a parent needs help? How do you bring up the subject? When you start having these concerns, it is time for "the conversation."

"No one plans to take care of a parent," says Virginia Morris, author of *How to Care for Aging Parents*. "So think ahead. Many preparations, such as buying long-term care insurance, must be done well in advance."

Getting involved in parent care does not mean controlling their lives. It means framing

questions and helping them make choices. The best way to start this process is to learn about home- and community-based programs. This can be done by calling the local Area Agency on Aging (AAA) and by searching Internet caregiving and aging sites.

The next step is communication: Set up a family meeting in person, by e-mail, in private Web chat rooms, or through telephone conferencing. Everyone possible should be involved: parents, adult children and their spouses, grandchildren,

and concerned relatives or neighbors.

"We need to break down communication barriers between adult children and parents that can leave a family at risk for exposure to financial, physical, and emotional consequences when Mom and Dad need long-term care," says Sandra Pierce-Miller, program director for the California Partnership for Long-Term Care. "Children have a pretty good understanding of what parents desire in terms of death and dying and estate planning, but no idea of the dreams and visions for the years when they may need long-term care."

Because it is not always easy to bring up these topics,

Resources

California Partnership for Long-Term Care
(800) CARE445, www.dhs.ca.gov/cpltc

Family Caregiver Alliance
(800) 445-8106, www.caregiver.org

HICAP, (800) 434-0222

National Association of Area Agencies on Aging
Eldercare Locator, (800) 677-1116, www.n4a.org

CAREGIVER WEB RESOURCES:

Administration on Aging
www.aoa.dhhs.gov/agingsites/default.htm

Consumer Health Interactive, www.ahealthyme.com

ElderCare Online, www.ec-online.net

Empowering Caregivers, www.care-givers.com

approaches might include:

- Saying you are beginning your own family's estate planning and need their advice.
- Sharing your emotional concerns directly.
- Assuring you do not want to take over their affairs, but are concerned that needs will be met, especially if a crisis occurs.
- Giving them a list of questions and scheduling time to talk later.
- Admitting you are worried about their driving, for example, and offering to find alternate arrangements.

In many instances, caregivers encounter resistance from parents who are embarrassed or who don't want to be a burden. In this case, it is wise to employ a third party professional such as a private geriatric care manager, a financial analyst, a therapist, clergy, or an elder care attorney to facilitate the proceedings.

The meeting should focus on facts and issues, not on negative emotions or past conflicts. Each person should be allowed time to share concerns and suggest solutions. Then family members can agree to specific actions, such as what help is needed and who will provide it. Even siblings who live far away can handle bills, make phone calls, or do Internet research. And remember that just because your parents have different views does not mean they are invalid.

Here are questions to explore at the meeting:

- What are your parents' perceptions about current needs and biggest worries?
- What are your parents' health conditions today? Future prospects?
- Is their home still accessible, or does it need modifications for disabilities and hazards? Is a move warranted?
- Do they need help with daily chores, meals, bathing, errands?

- Can they still drive safely?
- What are your parents' current and future financial needs? Do they need planning assistance?
- Have they executed the necessary legal papers (wills, trusts, powers of attorney), and are they up to date?
- Do they have adequate health insurance and long-term care insurance?
- What are their wishes for end-of-life care?

Not every family succeeds in getting their parents to do some early planning. But the risks of *not* even trying to have this conversation are significant. Caregivers can become so overburdened that their physical health collapses; their fatigue and frustration can lead to depression and even divorce; a lack of sufficient legal and financial planning can send a family into bankruptcy. Not only are most of the costs of long-term care not covered by health plans, but many caregivers also cut back on work hours or quit altogether in order to provide care. In the worst of scenarios, some caregivers have even died before their loved ones because of the stress.

Pierce-Miller cautions that families need to make a paradigm shift in thinking about long-term care, from the notion that remaining at home is always best to realizing that assisted living residences may be a better option, both financially and emotionally, especially if there are no caregivers available.

"We don't walk away from our parents when there are physical, financial, and emotional issues," she says. "We step in and take care of them. This is about relationship."

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